Statement of Dr. Wayne Taylor, Leukemia Survivor

On behalf of the Leukemia & Lymphoma Society

21st Century Cures Roundtable – August 19, 2014

My name is Wayne Taylor and I'm an Internist and a leukemia survivor from Hudson, Florida and I'm excited to participate in this initiative towards improving the development and access to cures in the 21st Century. Thank you to Congressman Bilirakis for inviting me to be here today.

In 2010, I was 52 and feeling tired. I thought I was just getting older- I was only half right. I had an aggressive form of acute myeloid leukemia (AML). I was fortunate to live close to Moffitt Cancer Center, an NCI designated cancer center, and I was hospitalized for 6 weeks and received the standard intensive IV chemotherapy regimen. Although there have been remarkable advances in Hematology since I underwent my medical training in the early 1980's, the standard induction treatment for AML is largely unchanged in 30 years. When the Head of Leukemia Section told me the treatment I would receive, my heart sank because I remember that was what was used in 1984, and I asked him 'isn't there anything better now?"

I failed to achieve a remission and I chose to go on a clinical trial that included a 'salvage' regimen of IV chemotherapy and an oral drug, Gleevec. Participating in a clinical trial may have been an easier choice for me as a physician, but only because I knew it was necessary for me. I am not a hematologist and choosing which clinical trial to enroll in was daunting and ultimately I went with what my hematologist thought was best . The result was that I achieved my first remission and only then could I be considered a candidate for a life-saving bone marrow transplant. I didn't match with my siblings, nor on the NMDP registry and again I was fortunate to be at Moffitt where I was offered a double umbilical cord blood transplant which was successful and I am here today.

My perspective as a 'physician-survivor' is a little unique. There are many patients who are diagnosed with AML whose story is not as fortunate as mine, as only 20% of AML patients survive five years after diagnosis. Through my participation in the Leukemia & Lymphoma Society and meeting with other survivors, I've observed some key areas of opportunity to improve the development and access to cures for cancer patients and I'd like to share three of them with you.

First, for many forms of blood cancer, having access to NCI designated cancer center like Moffitt is an essential part of diagnosis and treatment. These centers are particularly critical for patients with forms of cancer that are difficult to diagnose or treat such as AML. When insurance plans limit access to these types of centers, such as what is currently happening in the federal health exchanges, it means that certain patients will get to benefit from the amazing care that I did whereas patients with insurance that is not as robust won't have that option.

Second, there is room for improvement in the clinical trial matching and selection process. I've heard from many blood cancer patients that this is a point where they feel 'lost', not knowing how to enroll, not understanding the nature of clinical trials in AML (there is no placebo control…), not being confident that they are being 'matched' with the optimal trial for their unique cytogenetics and sometimes simply not being able to travel to the participating cancer center. I think that information systems should be able to link the key unique digital data that describes a particular patient with the current optimal clinical trial available for that patient.

New drug entities can take years to be delivered to the bedside if there is not statistically significant participation in their clinical trials. Partnerships by/between NCI cancer centers, the FDA and pharmaceutical innovators are needed to meet the challenges of enrolling, educating and matching patients with the optimal trial. It's conceivable that improving the efficiency of this cycle could actually lower some of the costs of bringing new drugs to market.

It's also important to understand that with the way we are targeting cancer today, through drugs that are developed using precision medicine technologies, smaller

clinical trials with specific sub-populations of patients will become the norm, and we need to make sure that the regulatory approval process accounts for this change in the way we treat diseases like cancer.

Lastly, I'd encourage Congress to look to some of the amazing partnerships and models happening in the private sector for direction on ways to advance drug development. One incredible example of this is LLS' Beat AML project, which is designed to find new treatments for this disease that I battled which hasn't seen a new standard of care in 30 years. Beat AML is a project privately funded by LLS that partners with several cancer institutions to collect and analyze samples from 900 AML patients over the next three years. By doing a full genetic sequencing exercise on these patient samples, we'll then partner with various drug manufacturers to test how different innovative medicines attack specific genetic mutations. These are the kind of collaborative projects happening around the country that can serve as a model for breaking down barriers between patients, academic centers and drug manufacturers.

I thank you for the opportunity to participate today and look forward to the continued conversation.